

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL
EDUCATION
Developmental Disabilities Committee Meeting

LOCATION
Westmark Hotel
Fairbanks, Alaska
Face-to-Face Meeting

Meeting Date
February 24, 2010

Attendees:

Kathy Fitzgerald, Chair
Ric Nelson, Chair
Jackie Hill
Bryan Knight
Steve Lesko
Lucy Odden
Emily Ennis
Velja Elstad
Kelly Donnelly
Kaleen Lamb
Maureen Harwood

Guests:

Dean Paul

Staff:

Duane Mayes
Carrie Predeger

Prepared by: Paula DiPaolo
Peninsula Reporting

Call to Order – 10:00 a.m.
Roll Call

INTRODUCTIONS, ANNOUNCEMENTS OR GOOD NEWS

Members of the DD Committee introduced themselves and provided other members with some background information about themselves.

APPROVAL OF THE AGENDA

Steve Lesko suggested adding a discussion of SB 109 to the old business. Kathy Fitzgerald also suggested adding time on the agenda for a current legislative update.

Steve Lesko made a **MOTION** to approve the agenda as amended. Lucy Odden **SECONDED**. The agenda was **APPROVED** as amended.

APPROVAL OF THE PREVIOUS MEETING MINUTES

Kelly Donnelly made a **MOTION** to approve the minutes from the previous meeting. Velja Elstad **SECONDED**. The minutes were **APPROVED** as written.

REPORTS

From the Chair

Kathy Fitzgerald stated that the Council serves as the Infants and Toddlers Coordinators Council and the Special Education Advisory Panel. The Council also has the Rural Services Ad Hoc Committee, the Autism Ad Hoc Committee and they have a really broad picture of how disabilities are working. She stated that they work with the State Independent Living Council and their sister boards through the Trust. She stated that the challenge is that the DD Committee is the core of the Council.

Kathy stated that things they need to focus on in this next session are the progress with the Long-Term Care Committee that Ric Nelson and Millie Ryan sit on. The Council will need to pay close attention to the recommendations in home and community-based services and how the waivers work in the state.

Kathy Fitzgerald stated that the Council's number one priority this year is ISIS, Intensive Support and Intervention Services, which is a missing piece of the system for individuals with developmental disabilities. Without this critical piece, people who are dually diagnosed will not be able to receive the supports they need to remain in their homes and communities and will continue to be at risk for placement at API or Outside in ICF/MRs. This program would give providers, family members and caregivers the expertise and training to be able to support those individuals.

Kathy stated that the Western Interstate Commission on Higher Education, WICHE, was funded by the Trust to study Alaska's system of care for individuals with complex behavior needs. They have completed their preliminary report which can be found on DSDS's website.

Kathy Fitzgerald stated that at this point, the commissioner is concerned about ISIS because he wants it to be broader and include mental health, older Alaskans, and TBI. Kathy feels that this is a Council project and would like to see it focused on the DD population only. A concern is that if this project fails, there is a risk of ICF/MRs coming back into the state.

Kathy stated that another issue that the Council has been very involved with is the passage of SB 32, which is to get a periodic rate review in statute for home and community-based services, just as they are for hospitals, nursing homes and institutions. Currently, they are in a system where they are not able to receive actual cost of living increases to do business. Without this, they are unable to attract qualified people to work for provider agencies.

Kathy Fitzgerald stated that another area the Council really needs to focus on is the moratorium and the fact that they need to be working with the State to know exactly what the corrective action plan contains.

Kathy also stated that she believes the DD Committee members should be well versed in advocacy. She can provide the training to the committee, but wanted to impress upon them the importance of understanding the role of advocacy for the Council. Steve Lesko also suggested adding to this piece a time to examine how the infrastructure of the State works so people know who they need to advocate and speak to. Maureen Harwood suggested that Marcy Rein might be able to pull this information together for them.

Action:

- Kathy Fitzgerald asked that Duane Mayes and Carrie Predeger begin to research information on the State's infrastructure.

Division of Senior and Disability Services

Maureen Harwood began her report by stating that Lynne Keilman-Cruz has moved over to head the assessment unit. She stated that she believes there are 937 people currently on the waitlist, and there was a draw of 50 people in January.

Maureen stated that they have just submitted the third revision of the corrective action plan for CMS and the documents are available online. She stated that it is at the state where it has been finalized and accepted. It will be made public the minute that every component has been settled.

She stated that they are doing very well with the MR/DD and CCMC waivers. They have no initial or amendments that were outstanding or had been in their office for more than 30 days. She stated that for OA and PD waivers, they have more volume, and there are still some assessments that are struggling. She stated that they are trying to do a better job in terms of their staffing, tracking and their technology to make sure that things aren't misreported. With the DS3 and other technology, they have a more division-wide picture of things.

Maureen Harwood further explained that the Division maintains four types of waivers, Older Alaskans, Adults with Physical Disabilities, Mental Retardation/Developmental Disabilities, and Children with Complex Medical Conditions.

Maureen stated that the STAR Program is the Short Term Assistance and Referral grants that some agencies maintain. The mini grants are funded through the Trust and are managed through Stone Soup Group. Kelly Donnelly stated that families really appreciate the system. They have a committee to evaluate applications and they are needs based as opposed to first come, first served.

Steve Lesko asked for more information about the waitlist numbers because he would like to see how those numbers were broken down in terms of people

who need full service and those who need partial service. Maureen stated that she can get that information to them. Kathy Fitzgerald also commented that the waitlist system was redesigned to be a triage system so that people who were in most need would receive waivers. People can also update their applications if their needs change. Maureen Harwood said that it would be interesting to see how the score range of applicants has changed from three years ago to today. Carrie Predeger commented that Marcy Rein used to give the DD Committee a one-page document that was a breakdown of the waitlist. Maureen stated that she will get that from Marcy. She also stated that the one-page sheet could maybe include the ages of applicants. Kathy Fitzgerald also asked if it could be broken down by region as well. Maureen stated that she believes they can track it by zip code.

Emily Ennis stated that the majority of referrals they get in their agency are children, and she would like to know whether or not that is the same experience with the State. She is wondering if that is reflective of whether or not they need to be building capacity for more children's services. She's also curious to know why they are not seeing more adults drawn. Emily suggested that this might be a good study for the Council to engage in.

Kathy Fitzgerald stated that the Council has worked very hard on early screening and diagnosis and they have seen a significant increase in statewide screening. For this reason, it would be nice to see the numbers as reflected by region. Emily Ennis also suggested tracking information related to the referral source.

Dean Paul suggested showing a documentary on how being on the waitlist impacts people to educate the population and the legislators.

Duane Mayes asked for a discussion on the current status of a quality assurance system as well as a discussion on expanding DSDS's staff and training. Maureen Harwood stated that Kara Thrasher-Livingston is going to get someone to work on the training piece. She is doing more advanced care coordination training. Maureen stated that she believes there is a lot of information online about the advanced care coordination training. One of the CMS requests was that they need to do critical incident training, and Kara is doing quite a bit of that online.

Maureen stated that in the Governor's budget, they had asked for more people. She stated that there will be an internal shift so that Kara can get

more help. Kathy Fitzgerald commented that Kara is a huge plus for DSDS and their training from the perspective of person-centered planning.

In terms of quality assurance, Maureen Harwood stated that they have a QA manager now and they are trying to address the QA concerns in their response to CMS. Kathy Fitzgerald commented that this has been something the Council has been strongly interested in.

Kathy Fitzgerald stated that the Supports Intensity Scale is something that many states are looking at using. She also shared her dislike of the ICAP. Maureen stated that this is something DSDS can look at and stated that there have been many discussions within the Division about using ICAP. She stated that Caroline Hogan, who does the ICAP assessment, has been calling other states to see what they are doing. Steve Lesko commented that one of the big objections to the ICAP from parents and providers is that it is a deficit-based assessment.

Maureen Harwood then explained the ICAP assessment process that determines whether or not someone meets institutional level of care. With that, then the person must also have a diagnosis under the federal definition. The ICAP is done when a person is drawn for a waiver. Kathy Fitzgerald further explained that when the waivers came into being, there were individualized dollars being spent for individuals based on what their need was. They were DD eligible, they met the federal level of developmental disability, but they didn't have to meet a level of care for an institution to get services. She stated that the waivers were going to allow providers to access federal dollars to provide the services.

AADD Report

Emily Ennis stated that the Association on Developmental Disabilities is an association of providers of developmental disabilities services. The AADD was formed for the basis to provide and support and act as a reference for providers as they began developing their services around the state. Today, the focus is still very similar and revolves around changes occurring in the state that affect the ability to do business and provide quality services. She stated that first and foremost is that they have to bring in the revenue to meet their expenses and all of the other associative responsibilities of business. She stated that they are mission based and want to provide the services that communities, families, and individuals need in a quality manner.

AADD's three areas of focus are rate methodology, rate review and the corrective action plan. Emily stated that they have been in a holding pattern because these three areas have great potential impact on their ability to do business and their ability to ensure quality services.

Emily Ennis stated that rate methodology is tied to the cost of doing business and they are concerned whether or not new rates are going to adequately cover the costs of doing business. The rates may be a little arbitrary in this next fiscal year based on some fairly narrow assessment of the cost of doing business.

Emily stated that the rate review, which is tied to SB 32, is very critical for the health of providers and the services needed. The current rates have been frozen for the last five years and they need a way to ensure that there will be a formal review of what it costs to provide services on a regular basis so that the State can project the costs of services in the future.

Emily Ennis stated that there will be an impact as a result of the corrective action plan and that some of the promises made to CMS will have a serious impact on their ability to do business.

Emily Ennis also commended the work of all the partners toward ending the movement to send people out of state to receive care. She stated that the bad news to this is that with the fiscal note, there is a disconnect with the Office of Rate Review and the actual cost of providing services that are needed to keep people in state.

Maureen Harwood stated that many people in the state have different voices and some people are asking for ICF/MRs. Kathy Fitzgerald stated that when providers and the community are not able to adequately address issues, then perhaps people feel as if that is their last option. She stated that they have proven, as demonstrated with the closure of Harborview, that they can provide those services in their communities, but they have had such a deterioration of their system that now it is difficult. Steve Lesko added that if parents see this as a desirable thing, he believes that if the community is invested in, people will get the same thing.

Key Coalition 2010 Platform

Steve Lesko stated that their priorities are:

- SB 32
- HB 187
- Infant Learning Program
- Adult dental
- Community Support Initiative
 - ~ Continue the waitlist reduction
 - ~ ISIS, \$650,000
 - ~ DD Community grants, \$200,000

OLD BUSINESS

Autism Private Insurance Reform, HB 187

Kathy Fitzgerald stated that HB 187 has a companion bill, SB 250. She explained the five-part autism initiative to the committee members which involves:

- Improve screening and diagnostic capabilities within the state
- Expand the Autism Resource Center
- Build on recruitment and retention strategies to keep people in the state to work in this arena
- Develop a way to pay for these services
- Develop an autism waiver or a way to fund intensive early intervention services.

Kathy explained that HB 187 addresses private insurance, not corporations who are privately insured. She stated that between 23 and 28 percent of the insured would fall under the private insurance segment. This insurance would pay for diagnostic screening and intervention services as long as it falls under scientific best practices.

Kathy Fitzgerald stated that there is progress with this bill and it has 19 sponsors in the House, and it is a committee bill on the Senate side.

She also stated that Autism Speaks did an independent study that shows that the premium increase would be under \$1.50 per month. The insurance companies are telling the legislature that this is a really expensive thing to do and that they may lose some insurance carriers if they decide to do this. Kathy stated that they just need to point out that it has been successful in other states and insurance companies aren't going to pull out because they

have less than a one percent increase.

Emily Ennis shared new data from a recent conference that shows that one of every 100 children is diagnosed with autism.

Statutory Rate Review – SB 32

Steve Lesko gave an overview of SB 32 and stated that for over 30 years, long-term care institutional programs have had a body that systematically adjusts their rates on two tiers. Every year they can get inflationary increases based on an adjusted census of who they serve, and that number comes from the consumer price index of a market basket approach. He stated that approximately every four years or so, they have rebasing.

Community-based services have had decreases over the last four or five years. He stated that if they lose all their community-based services to long-term care institutions, the costs would be astronomical and in the range of billions of dollars. Senator Johnny Ellis commissioned a study that clearly outlines this data.

Steve Lesko stated that they clearly want this to be in statute, not regulation. They want the same thing that nursing homes and others have.

ISIS

Kathy Fitzgerald stated that at the closure of Harborview, there was \$450,000 set aside for supports for people that were having challenging behaviors in the community. She stated that the \$450,000 just sort of disappeared within the state and a system was never developed. She stated that as a result, there has been an erosion in funding and training, and staff don't have the technical support or the expertise to do behavioral assessments.

Kathy stated that they are now in a position where families are desperate for help and the easiest thing to do is send people Outside because there is no structure for this in Alaska.

The Council has made this recommendation in the past and it didn't go anywhere. This year, the Trust came on board and made the recommendation to the Governor for the ISIS funding to move forward. The Council and the Center for Human Development outlined the talking points

and the budget for ISIS. The program would focus on assessment, intervention, training and prevention.

Duane Mayes stated that this funding request didn't make it into the Governor's proposed budget. They had a meeting with the Governor, who had also invited Commissioner LeDoux as well as other staff, and Millie Ryan and Kathy Fitzgerald took the lead on discussing ISIS with them. He stated that after the meeting with the Governor, there was another meeting between Commissioner Hogan, Pat Hefley, Melissa Stone, Rebecca Hilgendorf, Millie Ryan and Duane Mayes. After that, they went to Juneau for the Trust meeting and talked to people there about it, and the sense that they got was that other beneficiary groups need to be included in ISIS.

Duane stated that they did that and talked to the Alaska Brain Injury Network and the Commission on Aging and AMHB/ABADA. They received an e-mail that said they still won't support it because they want the money put into WICHE. Duane stated that it appears that they are going to have a tough time getting ISIS in this year unless they go for a capital request, as was recommended by Jerry Gallagher.

Kathy Fitzgerald stated that she doesn't think they can wait for WICHE because the longer it takes, the more people go Outside. She also stated that although she is very supportive of the sister boards, this issue is a Council priority. She stated that they have to develop the system and work within it right now. She also stated that she is a champion for TBI and for seniors and they need supports and services as well, but she believes they need to focus on their own because they are the ones hemorrhaging here.

Kathy further explained that the purpose of the ISIS system is to provide families, caregivers and providers with an option for dealing with these most extreme challenges when the current community system is not working for them to help individuals with challenging behaviors stay safe and receive the treatment they need in their own communities. She stated that people with developmental disabilities and autism do not belong in North Star or API, but that a system needs to be in place to provide resources and training in the community-based setting.

Duane Mayes read from the WICHE report, which under the first recommendation under children and adults read: Implement a demonstration project through an RFP process consisting of three to four small ICF/MRs or

other intensive structured alternatives specializing in the treatment of individuals with complex behavioral challenges. There was a group discussion around this recommendation during which Maureen Harwood stated that she understands that this could be like a child congregate emergency center. Kathy Fitzgerald stated that people would only be interested in this as an option as a result of there being no other intervention response available to them. Kelly Donnelly shared that her experience through Assets has shown her that people don't want to go to an institutional-type setting. ISIS is more respectful of individual rights.

Kathy Fitzgerald also commented that the Council was not asked to participate in the WICHE panel and there really wasn't any community representation. It was a panel of State people and department heads. Duane Mayes stated that Jeff Jessee stated that they can get the Council to be included and noted that Millie Ryan was invited to an upcoming meeting.

Duane stated that the deadline for putting in a capital request is February 26th and Patrick Reinhart is in Juneau meeting with legislators trying to get them to support a capital request for ISIS if it is not going to make it into the operating budget.

Kathy Fitzgerald also shared her disappointment with the fact that the Department and the commissioner are not behind this initiative after all of the conversations they've had with them.

Emily Ennis shared that this is a double whammy in that they don't have access to specialized training for their staff and they have a workforce that needs more training. They are not getting the qualified, experienced personnel that they need to provide the appropriate care. On top of that, they are also battling with the basic cost of providing the extra supports. She stated that they are being incapacitated on a provider level as far as their ability to serve, and families desperately need these supports; they're in crisis.

Jackie Hill stated that at the Disability Law Center, they have families call with very challenging problems, but they never call and ask for an ICF/MR. They call and say that they are at the end of their rope and don't know what else to do. People get left at psychiatric hospitals because no one knows what to do with them.

Steve Lesko made a **MOTION** for the DD Committee to make a

recommendation to make a capital request for ISIS. Lucy Odden **SECONDED**. The motion was **APPROVED**.

Steve Lesko asked for a clarification on what the State means by “small ICF/MR”. There was also a discussion on how people with developmental disabilities are unnecessarily influenced by the behavior of other residents when placed in API, and oftentimes, they come out worse than they were when they went in and now exhibit increased behaviors as a result of that placement.

Residential Services Summit

Kathy Fitzgerald stated that the Residential Services Summit was last May and was the result of the DD Committee examining residential services in Alaska and exploring other options that other states are using. She stated that the two areas they looked at are what technologies are available for use in residential settings and also to further examine intentional communities.

Kathy stated that intentional communities are a group of people with and without disabilities who have a thematic interest in belonging to this community.

Duane Mayes stated that the summit facilitator created a report focusing on three areas: Rest Assured, smart homes, and intentional communities. He stated that the Commission on Aging made a recommendation that some of the equipment and tools from Rest Assured be used to demonstrate an urban home and a rural home. The recommendation did not go through.

Duane stated that Rest Assured uses an electronic monitoring system that has both pros and cons in terms of privacy. He stated that they may take a team to Indiana to look at what Rest Assured has available. He stated that Assets is using some of these technology pieces and The Arc wants to pilot it as well. Kathy Fitzgerald further explained that the technology involves having cameras in the home in lieu of having staff around all the time. She stated that it’s a nice option, but may not be for everyone. She also noted that this might be a nice option for seniors.

Kathy Fitzgerald suggested that they follow up with Assets and The Arc to get a status on where they are at and how the program is working at Assets.

Duane Mayes stated that the smart home is a collaboration of AbleLink, who provides the technology, and Imagine, who provides the state-of-the-art home in Colorado. Duane stated that he and Kathy Fitzgerald met with AbleLink while they were in Colorado.

Kathy Fitzgerald stated that they have a computer program that she found very interesting that narrows down a job focus based on people's interests. This is something she would like the Department of Education to purchase. Duane Mayes stated that they had agreements and sold that product to VR programs throughout the country, and noted that it is a great tool to assess someone's interests.

Duane stated that he and Kathy then visited a smart home in Boulder. Kathy stated that she felt it was a little institutional and felt a little cold. She stated that they had keys that they had to use to check in to the smart home when they returned to it. The key is coded with what they are allowed to do in the home, such as use the stove. She stated that the rooms looked like a hospital setting, but some of the technology was really wonderful.

Duane Mayes stated that he will keep the committee updated on their ability to fund a small group to travel to Rest Assured in Indiana.

Steve Lesko stated that with the Council's assistance, Hope is going to be looking at investigating 70 to 100 acres in Southcentral to build an intentional community and design it around the needs and the visions of the people that will be a part of that. He stated that it's one of their chief priorities and they are going to begin to look at that in about a month.

PUBLIC TESTIMONY

The business meeting was recessed to allow for public testimony. The full transcript was prepared and public testimony can be found on page 223.

RECESS

The DD Committee recessed at 5:15 p.m.

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EDUCATION
Developmental Disabilities Committee Meeting

LOCATION
Westmark Hotel
Fairbanks, Alaska
Face-to-Face Meeting

Meeting Date
February 25, 2010

Attendees:

Kathy Fitzgerald, Chair
Ric Nelson, Chair
Jackie Hill
Bryan Knight
Steve Lesko
Lucy Odden
Emily Ennis
Velja Elstad
Kelly Donnelly
Maureen Harwood

Guests:

Dean Paul

Staff:

Duane Mayes
Carrie Predeger

Prepared by: Paula DiPaolo
Peninsula Reporting

CALL TO ORDER – 9:00 a.m.

OLD BUSINESS, CONTINUED

Duane Mayes recapped yesterday's discussion on the Residential Services Summit and noted the following action items:

- Follow up with The Arc of Anchorage and Assets to see where they are at with their efforts to pilot an electronic monitoring system
- Explore funding to take a small group from the DD Committee to Indiana to investigate the Rest Assured program in Indiana
- Take a trip to an intentional community that has been in existence for a while
- Get information from Tonja Rambow and Roy Scheller from Hope about the intentional communities they visited around the country and in Europe
- Create a document on the aspects of AbleLink that would be of benefit to people in Alaska
- Smart homes appear to have an institutional-like feel to them and the group didn't feel like pursuing that option would benefit them.

Ric Nelson and Kelly Donnelly shared their experiences visiting intentional communities, both good and bad.

REVIEW OF THE DD WORK PLAN

I. Accurately define service needs among people with developmental disabilities to establish a basis for advocacy and planning.

A. *Increase Direct Service Workers to a living wage.*

Emily Ennis stated that for the last three years, ANCOR has had a bill sponsored in the Congressional House of Representatives regarding wage parity and bringing greater attention to the wages paid to direct service professionals. She stated that in the current economy, it has been in a holding pattern. Emily also noted that the issue of health care reform has also not been helping it either in terms of the rising cost of Medicaid.

Emily stated that there is a shortage in the workforce and they need to be able to recruit. There will be more demands on the workforce over the next ten

years because of the senior population. They need to be able to attract and keep good quality employees. She stated that she heard someone speaking about one way to address this is to place a greater emphasis on interns and volunteers, but she noted the management risk element in that.

Steve Lesko stated that in the best case scenario, they get SB 32 passed, but that still won't catch them up. That still will not catch up direct service professionals. He suggested that they work with the UCEDD and ask if they would start a study to determine what the living wage should be and how it would affect people who are on public benefits.

The group discussed the snowball effect of the inability to attract qualified workers and supervisors.

Action:

- Kathy Fitzgerald stated that they can make their activity be to compile some studies to see what they can do to be ready once SB 32 passes and be prepared to move forward.

Kelly Donnelly suggested exploring options for federal support separate from what ANCOR is doing. She stated that staff in Senator Murkowski's office led her to believe that there may be support with a limited federal appropriation to assist with helping their direct service workforce. Kathy Fitzgerald suggested they do some strategizing about working with their delegation on moving that forward in Alaska.

Kathy Fitzgerald stated that she believed that the rate review and cost methodology were going to bring people at least back up to a level they were at five years ago prior to the rate freeze, and then have a cost of living increment to reflect doing business in 2010. She stated that this doesn't look like it's going to happen, so they have no other choice but to go back and start pushing for an increase.

Emily Ennis stated that as she understands it, for FY '11 starting this July, they will have some imposed rates based on the Myers & Stauffer average costs, some aggregate rates based on a small sample. During the next year, FY '11, they will follow a rate methodology review process and all of the providers are going to be asked to keep track of their costs with a universal format. Once all that information is compiled, the plan is to make rate adjustments for FY '12.

She stated that with this process, it might be two years before they determine that their costs aren't being covered and make some adjustments.

Kathy Fitzgerald stated that individuals and families will bear the brunt of whether or not this rate review is correct or incorrect. Emily Ennis stated that this year, they are approaching a time where there are a lot of unknowns in terms of predictability of their ability to hire and pay. The corrective action plan will have some fiscal impact too. Steve Lesko added that this issue could blow the socks off of community programs and he feels that it needs to be monitored very carefully.

Kathy Fitzgerald made a **MOTION** that they keep the increase in direct service workers' living wage as their goal with the activity being to gather data this year. Steve Lesko **SECONDED**. The motion was **APPROVED**.

Action:

- Contact Karen through the Center for Human Development and gather all information out there, including information from the Trust.
- Emphasize the inadequate rate structure to the Office of Rate Review and/or the commissioner
- Send a letter to the Governor and the ORR asking that they look at the impact for direct service workers
- Look at the historical perspective of direct service workers wages in the study that they will design
- Gather the data and form a subcommittee to review the findings
- Explore the elements that were used to come up with the rate in the rate methodology
- AADD and SDS will keep the Council apprised of the status of this issue so that they are informed and as up to date as they need to be.

B. Improve the data collection system of the DD Registry.

Maureen Harwood updated the DD Committee with the current DD registry information. She stated that as of yesterday, there were 996 people on the waitlist with 25 people in the cue. She will sit down and talk to Caroline about breaking it down by age scores and regions, but she doesn't believe it will be addressed right now because of all of the other priorities that SDS currently has. She stated that with the DS3, they are able to pull out more information than they have ever had the capability to do, but there is always room for

improvement. She also reiterated that most of the referrals they get are from the STAR Programs and community grantees. Kathy Fitzgerald suggested that it would be interesting to see how many referrals come from ADRCs. Kathy also stated that they would also like to have a report on the time it takes from being approved for a waiver to the development of a plan of care to implementation because of the inability to find direct care. She stated that quarterly data would be good to review.

Action:

- Kathy Fitzgerald stated that for item B-1, the status will be that it is done. For B-2, the status will be to continue to monitor. B-3 will have a status of ongoing.

C. *Support the Family Waiver Training and make certain that families on the DD Registry are invited to the trainings.*

Kathy Fitzgerald and Jackie Hill travel around the state to do Family Waiver Training to assist families in applying for waivers and understand the plan of care process. Kathy Fitzgerald stated that this is funded through SDS. She stated that she would like to see other people be trained to provide this training. She also stated that she would like to see them expand the peer-to-peer component of this similar to the old Family Resource Project so that there will be more families in communities with the ability to mentor. Kelly Donnelly stated that this is an ideal way for Stone Soup Group to partner around some of the family to family projects.

D. *Continue to participate in the Ad Hoc Committee on Autism to develop support for the recommendations for the legislature and the administration.*

Kathy Fitzgerald stated that the Ad Hoc Committee on Autism, along with a broader community of stakeholders, attended a meeting earlier this month to look at where they were at and to also look at the national initiative that is in conjunction with child and maternal health. That team will be meeting again on March 18th to address the next phase.

She stated that the committee has always been working on the five-part autism initiative and is now focusing on the funding piece, HB 187, the private insurance for autism services, and also looking at funding services through a

waiver or a Medicaid process. She stated that the primary focus with this is on early intervention services.

Action:

- After the meeting on the 18th, Kathy Fitzgerald will be bringing the DD Committee the recommendations that come out of that meeting.

E. *Work with SDS to implement the supported employment recommendations.*

Duane Mayes stated that Jennifer Jones has recently come on board with the role of working on improving some of the policies around supported employment in the State system. She has been working closely with Angela Salerno. She is housed within the Council office, but is technically employed with SDS and is funded through the Medicaid Infrastructure Grant.

Kathy Fitzgerald suggested pulling up the information gathered from the Supported Employment Committee, where they identified some major barriers to providing supported employment, and share it with Jennifer to get her input prior to the May Council meeting.

Action:

- Invite Jennifer Jones to the DD Committee meetings to provide supported employment updates.

Emily Ennis shared a couple of concerns that had been identified regarding supported employment. One of the biggest concerns was the change to Medicaid waiver billing in 15 minute units. Another significant change was that providers were only able to bill when a provider had face-to-face contact with an individual on the job site, which really means that they are only able to bill for 50 percent of the work that is done around a supported employment plan.

Carrie Predeger commented that the Council's website has a link to the Supported Employment Committee's formal report.

F. *Study on Adult Public Assistance rates in order to possibly recommend an increase.*

Carrie Predeger stated that they looked at this issue in '09 and stated that it is a touchy subject because Alaska has public assistance for adults when many other states do not. Kathy Fitzgerald suggested that as an action item on their work plan, they might refer this issue to the Trust because many beneficiaries are impacted by this. She also suggested exploring a strategic plan around this with some of the other partners.

Action:

- Staff to discuss issue with the sister boards to what kind of data they need to gather in order to bring this forward and possibly do some strategic planning. Staff will report on their findings at the next DD Committee meeting.

G. *Establish a housing workgroup to look at affordable, transitional housing resources for individuals with developmental disabilities.*

Duane Mayes stated that he is part of the technical assistance team for the housing focus area of the Trust. He stated that he has noticed and has heard from other DD providers that the housing plans seem to lean heavily toward behavioral health. He stated that there are Special Needs Housing Grant (SNHG) dollars that DD providers feel are not for them, but Duane believes that they are. He suggested to the technical assistance team that they could do a workshop to talk to DD provider organizations about how they can access these dollars so they can get their piece of this pot of money. He stated that they agreed to that.

Duane stated that he also spoke to Nancy Burke who agreed that she would sit on a work group that would be a subcommittee of the DD Committee that could focus on housing. She would be able to help the members better understand the logistics of SNHG and the Homeless Assistance Program (HAP).

Emily Ennis stated that she looked into those funding opportunities and when she read closer, she stated that the element of homelessness must be tied into it. She stated that they don't have any evidence of that because they work really hard to make sure the individuals they support are never homeless.

Duane also stated that he has joined the Program Evaluation Committee and has a box full of applications that he is going to be reviewing to try to get an indication of how they might get a part of that money for DD provider organizations. Emily Ennis stated that she would like Duane to share with them information he is able to gather about allowing people to construct or rehabilitate homes to make them more supportive for people with destructive behaviors. She would like to know what people have proposed to address folks with those needs.

Emily Ennis also commented that DD programs have never had the funding assistance for housing the way that behavioral health providers have.

Action:

- Kathy Fitzgerald asked that Duane Mayes share the information he's learned with Bryan Knight and also see if Bryan, Emily and Steve might want to be a part of the housing group.
- Continue to research and explore housing funding options for DD providers.

H. Support self-advocacy organizations.

Lucy Odden stated that she and Millie Ryan held a workshop last may to see if they could get a People First chapter throughout Alaska. She stated that the only communities that have responded with any interest are Anchorage and Fairbanks. She stated that at the workshop they also discussed building a better website.

Kathy Fitzgerald stated that as part of their five-year plan, they can focus on some of the peer-to-peer mentoring and support amongst self-advocates. She also noted that there is a fine balance between helping and interfering and promoting independence and enabling.

Action:

- Explore how to best promote self-advocacy in Alaska and some different approaches than have been tried in the past.
- Identify the range of self-advocacy organizations that are available in Alaska and explore how to connect them so they communicate.

Kelly Donnelly made a **MOTION** for the DD Committee to request that the Council host a listing of advocacy groups and meeting times so the information could be shared at a central location. Jackie Hill **SECONDED**. The motion was **APPROVED**.

RECESS

The meeting was recessed at 12:00 p.m. to prepare for site visits.

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL
EDUCATION
Developmental Disabilities Committee Meeting

LOCATION
Westmark Hotel
Fairbanks, Alaska
Face-to-Face Meeting

Meeting Date
February 26, 2010

Attendees:

Kathy Fitzgerald, Chair
Ric Nelson, Chair
Jackie Hill
Bryan Knight
Steve Lesko
Lucy Odden
Emily Ennis
Velja Elstad
Fred Villa

Guests:

Dean Paul

Staff:

Duane Mayes
Carrie Predeger

Prepared by: Paula DiPaolo
Peninsula Reporting

CALL TO ORDER – 9:15 a.m.

REVIEW OF DD WORKPLAN, CONTINUED

Duane Mayes shared some information he was able to get from Jennifer Jones. He stated that the comments from the stakeholders from the Supported Employment Committee were as follows:

- Fear of losing health benefits
- Financial disincentives
- Fragmented systems
- Lack of comprehensive vocational services that include benefits counseling
- General lack of knowledge or use of existing work incentives
- Limited work opportunities.

Duane stated that the Supported Employment Committee report contained further information that stated that with a commitment from the DSDS, there is now dedicated staff to work on policy and practice within the Division on supported employment.

A developmental disability supported employment task force met and proposed changes that would make a difference in improving employment outcomes for people with developmental disabilities in Alaska. The issues identified for change are as follows:

- Lack of clear specific employment policy
- Lack of specific policy around supported employment and self employment
- Regulations are needed that are tied to funding incentives
- A lack of systemic approach to the use of assistive technology
- MR/DD policy encourages a glomming onto the person in order for the person to get paid
- The 15 minute unit does not work effectively in supported employment
- Supported employment does not fit into the medical model
- Rates
- Build in some factor of difficulty in placing certain individuals
- Put enhanced rates in the waiver plan.

Action:

- Duane Mayes will send the DD Committee members a copy of that report.

LEGISLATIVE ISSUES

ISIS

Duane Mayes stated that Patrick Reinhart was in Juneau this week and Duane had asked him to meet with some of the legislators around the issue of ISIS with the intent that he would be asking for an operating increment, and if they can't get the operating increment, go for a capital request.

Duane read Patrick's meeting notes to the DD Committee members. In summary, Senators Meyer and Davis were agreeable to ask Senator Olson to put the \$650,000 into the budget. Senator Olson's staff stated that it will be considered with other worthy projects. Senator Meyer asked if they would compromise on the amount and go for half.

Steve Lesko asked if the Trust would be willing to fund it as a pilot project. Duane Mayes stated that he talked to Nancy Burke and she suggested they contact Jeff Jessee to see if he can help to get the full amount into the operating budget.

Kathy Fitzgerald reiterated her strong feelings that this is strictly a DD issue and does not include all of the other beneficiary boards, some of which don't even include ISIS as a priority of theirs.

Steve Lesko suggested telling the legislature that they will accept the half and then get the Trust to fund the other half as a pilot.

Kathy Fitzgerald made a **MOTION** that the DD Committee recommend that they focus this as a DD initiative with perhaps a partnership with seniors at some point early on and the other boards later should they decide to join them; that they go for operating, and if they can't, ask for capital through a pilot project. Lucy Odden **SECONDED**.

Steve Lesko asked Kathy if she is suggesting that they go for the entire \$650,000 without the Trust putting in funds at this point. Kathy Fitzgerald

stated that they will need to have a discussion with Jeff Jessee to see if the Trust would be willing to fund this.

Kathy Fitzgerald **AMENDED THE MOTION** to add that there is urgency to this issue and that DD can't wait and they recommend that the Trust support them in moving this forward this year.

Steve Lesko made a **MOTION** that they table this motion until they are able to talk to Jeff Jessee. Lucy Odden **SECONDED**. The motion was **APPROVED**.

Legislative Priorities

Duane Mayes stated that during the full Council meeting, legislators were given packets and informed of the Council's priorities which include: HB 187, SB 109, SB 32, ISIS, and the Disability Program Navigators. They also provided the Governor with a packet that involved ISIS and the State being a model employer of people with disabilities. They have agreement with the Governor and Commissioner Kreitzer to do a statewide survey of all State employees to find out whether or not they have received accommodations when they went to work in a particular division.

Duane stated that they also had a discussion with the Governor about the deaf community's interest in having a deaf center. He stated that in some discussions with legislators about this issue, they were interested in a co-op approach with several non-profit agencies working together under one roof. There were a couple of representatives that have expressed interest in submitting a \$50,000 capital request to do a need assessment to explore whether or not that's feasible for next year. Senators Meyer and McGuire have expressed interest in supporting this issue.

REVIEW OF THE DD WORK PLAN, CONTINUED

- II. Promote the establishment of a comprehensive, outcome-based fiscal and programmatic quality assurance program.**
- A. *Work with SDS to assess and make recommendations for a meaningful QA process and system that includes a peer review and consumer satisfaction.***

Kathy Fitzgerald stated that she believes this issue needs to be addressed in

SDS's corrective action plan.

Duane Mayes stated that he talked to Carol Downey, who is no longer the lead for QA with SDS, but she had stated that they were feeling very overworked and they didn't have enough staff to formalize and put together any kind of quality assurance.

Fred Villa suggested that the committee specify steps to take regarding this issue rather than just state "continue to monitor the situation".

Steve Lesko suggested finding out who the person is that is working on quality assurance with SDS and invite them to a future DD Committee meeting to give them a status update. They also need to impress upon SDS that there should be stakeholder input into this process. Kathy Fitzgerald also noted that they should let the Trust know that they are asking for this information because they are not the only beneficiary group that has asked for it.

Action:

- Staff are to research who the quality assurance person is with DSDS and invite them to attend a DD Committee meeting to provide an update on the quality assurance process.

MORNING STAR RANCH

Karma Brown from Morning Star Ranch gave a presentation of their program. She stated that the mission statement for Morning Star Ranch is to use the farm and ranch setting to enhance the quality of life for individuals of all abilities through education, activities and work experience.

She stated that they are a non-profit program and have been billing Medicaid since 2000. They provide day habilitation and respite care. All of the people that attend Morning Star Ranch are on the MR/DD waiver.

Karma Brown stated that activities they do at Morning Star Ranch include, but are not limited to:

- Gardening
- Petting zoo activities at fairs
- Wood working

- Games, newspaper activities
- Crafting, exercise activities, cooking
- Horseback riding, camping, hiking, fishing
- Movies, computers, Wii
- Grocery shopping, community activities, university, Go-Karts of Alaska.

They also collaborate with other non-profits in the area to serve families.

Karma Brown shared a video of Morning Star Ranch and concluded her report.

REVIEW OF THE DD WORK PLAN, CONTINUED

- III. Support, monitor and track Alaska Mental Health Authority Focus Areas.**
- A. *Participate in the Trust area workgroups of Bring the Kids Home, Trust Beneficiary Project Initiatives, Disability Justice, Housing, and Workforce Development.***

Kathy Fitzgerald stated that there is regular communication between Council staff and the Trust and they are kept abreast of all the information, both verbally and through written reports.

- 1. Provide update on two focus areas at DD Committee meetings.**

Kathy Fitzgerald stated that staff don't report on areas unless there has been any change in status or any action. Duane Mayes stated that if committee members are interested in participating in any of the focus areas, staff can provide them with the notes and minutes of those meetings.

FURTHER DISCUSSION ON ISIS

While they were waiting for a call back from Jeff Jessee, the committee felt they should take time to formulate specific information to present to Jeff in regards to the ISIS situation that has developed. In summary, the ideas that they would like to present to Jeff Jessee are:

- Enlist Jeff's help in carrying the message forward to the legislature that the Council wants to have \$650,000 put into the operating budget to

fund ISIS for the DD community only.

- If the push for the operating budget fails, would the Trust be willing to look at capital?
- A reminder to Jeff that this is the Council's number one priority.
- Would the Trust be willing to fund a demonstration project with a split between the State and the Trust?

Kathy Fitzgerald also shared concern that these monies not be channeled through DSDS, but rather somewhere outside of the Department.

Duane Mayes sent an e-mail to Millie Ryan to inform her that the DD Committee has a call in to Jeff Jessee in regards to the ISIS issue. Millie was concerned that the information they have been giving the legislators talks about a broader population than just DD. She stated that the Commission on Aging and the Alaska Brain Injury Network are still very interested. She felt that they wouldn't have the Trust's support if it is just DD given the recent conversations she has had with Jeff Jessee.

Kathy Fitzgerald stated that she spoke with Millie and noted that the current fact sheet on ISIS is very broad and specifies DD community grants. It does not mention behavioral health, seniors specifically or TBI. Kathy said that Millie relayed to her that she is not sure if the Trust will support it if they say it's just for DD.

Kathy stated that an additional question to Jeff Jessee will be:

- What is the Trust's position on the ISIS sheet as it is written?

REVIEW OF THE DD WORK PLAN, CONTINUED

IV. Track and monitor the Medicaid/Medicare system.

A. *Coordinate advocacy efforts with Key Coalition.*

The activities that the Council does to coordinate advocacy efforts with Key Coalition include, but are not limited to:

- Funding all Council members to go to Key
- Provide \$5,000 in stipends for others to attend Key
- Council staff attend Key board meetings

- Council and Key priorities are aligned
- Legislative Committee also supports Key.

Action:

- Carrie Predeger and Duane Mayes will bullet out the specific activities that the Council participates in regarding their advocacy efforts with Key.

Fred Villa asked how goal IV-A relates to the Medicaid/Medicare system. He suggested that for the next year's work plan, they look at all of the activities to see how they relate to the goals and perhaps restructure them where necessary.

B. *Advocate for increase reimbursement rate for Medicare as it affects access to medical care.*

Kathy Fitzgerald shared that the history behind this was from Bryan Knight voicing his concerns about his inability to access health coverage because physicians wouldn't accept Medicaid/Medicare. Ric Nelson stated that he also couldn't find a general practitioner for a year.

1. *Partner with AARP, ACoA, and the Primary Care Association to bring the issue of Medicare physician shortage to the attention of the public.*

Kathy Fitzgerald stated that they could put on the work plan the status that it has happened, because they had an increase in their Medicare reimbursement rate as a result of it.

Steve Lesko stated that a study should be done on the factors of why physicians don't accept Medicare. Kathy Fitzgerald suggested seeing if UCEDD or any other groups have done a study.

C. *Monitor and comment on the development and implementation of a state rate methodology and review process.*

Kathy Fitzgerald asked if staff or any Council members have participated in the cost rate review study through SDS. Duane Mayes stated that he didn't think so.

Steve Lesko stated that they need to make it clear that the cost methodology and the rate review are two separate things. He also asked if staff could keep a diary of the different meetings they have attended to be sure that there is representation from the Council wherever it is needed. Kathy Fitzgerald stated that they should see if they can persuade the Division to have Council representation on this committee if they do not already have a seat.

Action:

- The DD Committee will ask the Executive Committee to send a letter to the commissioner requesting formal representation.

D. *Identify, monitor and recommend solutions on Medicaid issues that affect individuals.*

Steve Lesko stated that he believes the Council needs to have more involvement with SDS in terms of the corrective action plan. He stated that Key, AADD and the Council have all been told that there was going to be a stakeholder group, but no one has heard any information about one. Steve stated that they need to be involved in the process before SDS submits something that the feds accept that the DD providers are then committed to.

Kathy Fitzgerald stated that she believes Disability Law Center's participation in this is also important. Jackie Hill stated that DLC would probably not be involved due to ongoing litigation surrounding the moratorium.

Fred Villa asked that committee members and staff make time to get together with him to further explain this issue to him as a new member.

Action:

- Make a formal request to SDS for stakeholder participation in the corrective action plan.

E. *Advocate for an individualized streamlined system of care vs. a programmatic system of care.*

Fred Villa suggested that in the status of this, they should put a note to further define what is meant by this activity. Emily Ennis stated that she believes it means to advocate for whatever it takes for an individual rather than just place

them in a slot.

Action:

- Define this activity prior to the next DD Committee meeting.

OTHER COMMITTEE BUSINESS

Future Meetings

Duane Mayes stated that they need to be thinking about the upcoming events of this year and decide when the next time to have a face-to-face meeting would make the most sense and be the most productive.

Budget Recommendations

In the discussion of creating Council priorities and making budget recommendations to the Trust, Emily Ennis asked if OMB gave a formal response about why they rejected their budget recommendations. She stated that Jeff Jessee had described the process to her which involved a clearly written reason for why it was rejected.

Action:

- Get a written response from OMB regarding rejected budget recommendations.

Current Version of ISIS Handout

Duane Mayes stated that there is a newer version of the ISIS handout than the one the committee members had been given. Duane read the newer version to the committee.

Kathy Fitzgerald shared her concerns with the language that discusses managing people's behavior because that does not represent the philosophy of the Council.

ADJOURN

After closing comments, the meeting was adjourned at 3:00 p.m.